

SCIENTIFIC METHOD —

New bill would let companies force workers to get genetic tests, share results

Under guise of “voluntary” wellness programs, employees’ genetics could be exposed.

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It’s hard to imagine a more sensitive type of personal information than your own genetic blueprints. With varying degrees of accuracy, the four-base code can reveal bits of your family’s past, explain some of your current traits and health, and may provide a glimpse into your future with possible conditions and health problems you could face. And that information doesn’t just apply to you but potentially your blood relatives, too.

Most people would likely want to keep the results of genetic tests highly guarded—if they want their genetic code deciphered at all. But, [as STAT reports](#), a [new bill](#) that is quietly moving through the House would allow companies to strong-arm their employees into taking genetic tests and then sharing that data with unregulated third parties as well as the employer. Employees that resist could face penalties of thousands of dollars.

In the past, such personal information has been protected by a law called GINA, the Genetic Information Nondiscrimination Act, which shields people from DNA-based discrimination. But the new bill, HR 1313, gets around this by allowing genetic testing to be part of company wellness programs.

Company wellness programs, which often involve filling out health surveys and undergoing screenings, are pitched as a way to improve employee health and reduce

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overall health costs. But, research has shown that they have little effect on employee health and may actually end up *costing* companies. Still, they may survive as a way to push healthcare costs onto employees. As [Ars has reported before](#), companies use financial incentives to get employees to participate in these wellness programs. Under the ACA, these incentives can include all sorts of rewards and compensations. For instance, people who don't want to participate can pay up to 60 percent more on employer-sponsored insurance premiums. That can easily amount to thousands of dollars each year.

Despite the heavy financial pressure, employee participation is still considered voluntary. Under HR 1313, GINA wouldn't apply to anything voluntarily collected through wellness programs, and companies would have access to genetic data. That information would be stripped of identifiers, but in small companies, it could be fairly easy to match certain genetic profiles to specific employees.

Moreover, employers tend to hire third parties to collect and manage health data. These companies are not heavily regulated and can review genetic and other health data *with* identifiers. Some of the companies even sell health information to advertisers, *STAT* notes.

Civil rights and genetic privacy advocates strongly opposed the bill. In [a press release](#), Nancy Cox, PhD, president of the American Society of Human Genetics said:

"We urge the Committee not to move forward with consideration of this bill. As longtime advocates of genetic privacy, we instead encourage the Committee to pursue ways to foster workplace wellness and employee health without infringing upon the civil rights afforded by [Americans with Disabilities Act] and GINA."

On Wednesday, the House Education and the Workforce Committee approved HR 1313 along party lines, with 22 Republicans supporting and 17 Democrats opposing the bill.

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